Medical Futility and Care of Dying Patients

NANCY S. JECKER, PhD, *Seattle, Washington*

In this article, I address ethical concerns related to forgoing futile medical treatment in terminally ill and dying patients. Any discussion of medical futility should emphasize that health professionals and health care institutions have ethical responsibilities regarding medical futility. Among the topics I address are communicating with patients and families, resolving possible conflicts, and developing professional standards. Finally, I explore why acknowledging the futility of life-prolonging medical interventions can be so difficult for patients, families, and health professionals.

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With the development of new medical technologies during the latter half of this century, medicine has been able to keep terminally ill patients alive for longer periods of time without curing or ameliorating their underlying disease condition. The widespread use of artificial feeding and nutrition, ventilator support, cardiopulmonary resuscitation, and renal dialysis has meant that patients diagnosed with metastatic cancer, coronary artery disease, kidney failure, and other life-threatening conditions no longer regard their diagnoses as lethal. Yet, life-sustaining interventions have sometimes been a double-edged sword. Medical treatments that extend life may also result in patients spending their final days and weeks confused and debilitated, unable to breathe, eat, or urinate without the assistance of ventilators, feeding tubes, and catheters. Although patients live longer, they may find themselves confined to hospitals and intensive care units, where they are sedated and unable to interact meaningfully or to obtain comfort and support from the company of others.

Under what circumstances should providers cease life-prolonging efforts? When a patient reaches the final stages of a terminal condition such as AIDS [acquired immunodeficiency syndrome], should the patient be admitted to a hospital for pneumonia, receive intravenous infusions for fluid loss with diarrhea, or be prescribed antibiotics for a bladder infection? What about more invasive procedures, such as the insertion of endotracheal tubes, the use of defibrillators, or surgical repair of a bowel obstruction? When should providers attempt to prolong life, and when should their efforts instead focus on palliative measures?

In this article I address the general problem of forgoing the use of life-sustaining medical treatment in terminally ill and dying patients. I defend a patient-centered definition of medical futility, placing it in the context of end-of-life care. The ethical responsibilities of health professionals and health care institutions are discussed with regard to communication with patients and families, conflict resolution, and the development of professional standards about medical futility. In closing, I explore the reasons why acknowledging the futility of life-prolonging medical interventions can be so difficult for patients, families, and health professionals. Despite possible obstacles, refraining from medically futile interventions is often the best way to care humanely for patients at the end of life.

What Does Futility Mean?

At first glance it might seem that, if a patient's death is imminent, then the patient's entire situation is futile regardless of what physicians do. On the other hand, if a life-sustaining treatment is working, that is, keeping the patient alive, we may wonder how the question of futility can even arise.

To clarify these questions, it is helpful to note that the term "futile" refers to a specific medical intervention applied to a specific patient at a particular time. It does not refer to a situation generally or to medical treatment globally. Nor should "futile" be used to refer to a patient, or to care, as this may convey the impression that the patient is being abandoned or that comfort measures will no longer be undertaken.

Finally, futile treatments sometimes succeed in producing physiologic effects, yet provide no benefit to the patient. For example, cardiopulmonary resuscitation of a permanently unconscious patient may restore heart function, yet be regarded as futile because it does not confer any benefit that the patient can appreciate. Those who regard the goal of medicine to be helping the patient, not merely producing effects on organ systems or body parts, accept what is thus called a "patient-centered" definition of medical futility.[1]

A patient-centered understanding of medical futility involves attention to situations in which many effects can

be produced on a person's body; only some will be appreciated as benefits, others will be perceived as harm, and still others will not be experienced by the patient at all. For instance, resuscitating a heart attack victim and returning her to full functioning is clearly a medical benefit. On the other hand, when an emergency medical crew is called to a nursing home to assist a patient who suddenly has dyspnea and ventricular arrhythmia, followed by cardiac arrest, and who is known to have widespread pancreatic cancer, the effect of attempted life prolongation may not be experienced as a benefit by the patient, but may instead be regarded as a detriment by adding to the patient's pain and discomfort at the end of life. In contrast to these situations, prolonging the life of someone in a persistent vegetative state through the use of a feeding tube is not experienced as either a burden or a benefit by the unconscious patient.

Futility may become apparent in the context of caring for dying patients in at least two distinct ways. First, a treatment may be quantitatively futile because the likelihood that it will benefit a patient falls well below a threshold considered minimal.[2] For example, it is futile for emergency workers to rush terminally ill patients to a hospital after a failed resuscitative effort in the field because there is virtually no chance that patients will survive and benefit from such efforts.[3,4] Second, a treatment may be qualitatively futile when the quality of benefit associated with an intervention falls well below a threshold considered minimal.[2] For instance, hemodialysis of a hospitalized patient dying of multiple organ system failure with no hope of survival to discharge is qualitatively futile.[5]

Some have objected to a patient-centered definition of medical futility, claiming that a treatment should be called futile only when it fails to produce any physical effect on the patient's body.[6,7] Supporters of a "physiologic" definition of futility argue that health professionals should avoid imposing their values on patients and families and that patient autonomy should be seen as inviolable.[8,9] Limiting health professionals' judgments about futility to the narrow, technical evaluation of whether a treatment can produce an effect may appear to rid futility judgments of any value dimension.

My response is that the goal of medicine is not merely to produce physical effects on patients' bodies, but to help patients.[10] Expressed differently, "the subject of medical care is the suffering patient, not a failing organ system."[1(p197)] In contrast to a physiologic approach, which pictures the health professional's role to be narrow, technical, and even value free, a patient-centered view regards the provider's role as promoting patients' good by producing effects that patients can appreciate.

This stance is consistent with the historical and contemporary ethics of the profession. Since its earliest beginnings, medicine has focused on the ethical goal of helping suffering patients. The ancient Greek physician, Hippocrates, reportedly identified the purposes of medicine as twofold: first, "to do away with the sufferings of the sick" and "to lessen the violence of their disease"; and second, to recognize medicine's limits, "to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless."[11(p6)] Reflecting a continued commitment to these goals, the American Medical Association (AMA)[12,13] and many other medical organizations have affirmed medicine's inevitable limits.[14-18] According to the AMA's Council on Ethical and Judicial Affairs, physicians' obligation is to offer patients "medically sound" options, including interventions that can "cure or prevent a medical disorder" or "relieve distressing symptoms."[12(p2230)]

In addition to ignoring the ethics and goals of medicine, a physiologic approach overstates the value of autonomy, casting it as an ethical absolute. Although respect for the wishes of autonomous patients is clearly an important value, this value must be placed in context. Autonomy does not entitle patients to receive any treatment they want, nor does it obligate health professionals to provide interventions that are "countertherapeutic" or that are contrary to "role-related professional standards and conscientiously held personal beliefs."[19(p44)] Upholding autonomy as an ethical absolute belittles the importance of beneficence in medicine, by making the goal of benefiting patients a secondary, or even irrelevant, consideration. If the only task of medicine were to carry out patients' wishes, clinicians would be reduced to functioning merely as patients' instruments. By contrast, upholding standards of medical practice aimed at benefiting patients assigns importance to beneficence while preserving a role for patient autonomy.

Finally, defining medical futility in purely physiologic terms fails to deliver on the promise of offering a "value-free" role for the provider. A commitment to use all interventions that can produce some effect on a patient's body, unless a patient or surrogate explicitly refuses them, is hardly a value-free stance. Instead, it implies a strong commitment to biologic life; a commitment to medical technology for its own sake, rather than as a means of promoting patients' good; and a disavowal of providers' ethical responsibility to promote patients' good and to avoid harming them.

What Are Providers' Ethical Obligations?

Once disagreements about the meaning of medical futility are resolved, there remains the question, What are health professionals' ethical responsibilities? Should providers offer futile treatments to patients or surrogates? Should providers instead explain and discuss the situation more generally? Should providers attempt to exclude a discussion of futile interventions with patients or families altogether, with an eye to preventing possible conflicts from arising? If conflicts do arise over the use of a futile intervention, what constitutes a fair process of conflict resolution? May a physician unilaterally override a

patient or family? Or should physicians instead cede to patients' or families' wishes?

Where feasible, providers should communicate in advance with patients (or surrogates) about decisions to withhold or withdraw futile treatments. Sensitive communication serves many functions, including making providers accountable for their decisions, educating patients and families, building trust between providers and patients (or families), and averting concerns that resources are being rationed or that patients will be abandoned. Providers should use the occasion of discussing the withholding or withdrawal of futile treatment to affirm that everything possible will be done to support the patient at the end of life, including the aggressive use of palliative and comfort measures.

Although the ordinary obligation of health professionals is to refrain from offering or using futile treatments, in certain situations compassionate exceptions should be made. For example, a patient with widespread cancer whose death is imminent within a matter of hours or days may ask to be made a "full code" because the patient would like to live long enough to see a grandchild for the first time who is arriving from a distant state. Or a patient who will never leave the intensive care unit may want to stay on a ventilator long enough to provide emotional support to a grieving spouse who is in the process of slowly coming to terms with the patient's death. Agreeing to a time-limited trial may provide a patient or family an opportunity to come to terms with their situation and to gain a sense of control over their fate. These examples make evident that the appropriate steps for implementing general ethical guidelines to refrain from futile interventions vary from case to case.

In the event that a patient or family persistently requests a treatment that the health care team regards as futile, a process of sensitively negotiating the conflict should occur. Ideally, an institution's policy on withholding and withdrawing treatment will specify steps for resolving conflict. These steps may include, for instance, consulting with the institution's ethics committee or individual clinical ethics consultants[20]*; drawing on resources such as a chaplain or social worker to provide support to the patient or family; obtaining a second medical opinion; and facilitating further communication with the patient, family, or both. In most cases, pursuing a process of conflict resolution enables the patient, family, and health care team to reach agreement and bring the case to a point of closure. Even when the parties continue to disagree about what should be done, they may be willing to accept a compromise position. For example, if there is not a clear consensus in the medical community about the futility of a particular intervention for the patient, the medical team may agree to refer the patient elsewhere. Or if a treatment is clearly futile, the patient or family may agree in advance to discontinue treatment after a certain amount of time if there is no improvement in the patient's situation.

The final decision about whether or not a particular treatment is futile does not rest with any single person. Rather, the definition of medical futility must be grounded in general standards of care that are first articulated by the health care professions and then accepted by the broader society.[21,22] Guidelines about medical futility should be based on reliable empirical data about the effects of interventions on different patient groups, as well as careful ethical analysis concerning patients' benefit. Whereas debate about the meaning of futility and ethical implications continues, physician surveys show that physicians are already incorporating some concept of medical futility into decision making at the bedside.[23-25] Establishing general guidelines and standards that address medical futility is preferable to delegating decisions about medical futility to individual physicians at the bedside. Bedside decisions are often not thought through, not applied consistently, not accountable to the public, not decided democratically, and not insulated from arbitrary or invidious prejudice based on factors such as a patient's race or ethnic group. To minimize possible abuses, institutions should develop clear standards for withholding and withdrawing futile interventions. Such standards serve to educate and guide not only patients and families, but also health professionals and courts about the limits of medicine.[26]

Many institutions have already begun to incorporate the concept of futility explicitly into guidelines for the withholding and withdrawing of medical treatment. For example, Johns Hopkins Hospital (Baltimore, Maryland) has defined "futility" as any course of treatment that "is highly unlikely to have a beneficial outcome" or "is highly likely merely to preserve permanent unconsciousness or persistent vegetative state or require permanent hospitalization in an intensive care unit."[27] Local consensus is also developing in places like Denver, Colorado, where area hospitals jointly developed criteria for deciding that a treatment is futile.[28] Such guidelines establish, for example, that aggressive treatments, such as cardiopulmonary resuscitation, are futile and should not be provided for patients who are bedfast with metastatic cancer, patients with AIDS who have had two or more episodes of *Pneumocystis carinii* pneumonia, or patients with multiple organ system failure with no improvement after three days of intensive care.

What Makes Acknowledging Futility So Hard?

Despite the importance of emphasizing patient benefit in the care of dying patients, health professionals often feel compelled to continue with nonbeneficial interventions. Interviews with physicians and nurses found that almost half (47%) of all respondents reported acting contrary to conscience in providing care to the terminally ill, with four times as many providing overly burdensome treatment than undertreatment.[29] Especially if a patient or family member requests that "everything possible" be done, the health care team may be reluctant to go against the patient's or surrogate's wishes. Unbalanced respect

for patient autonomy, well-meaning compassion for grieving family members, fear of legal liability, and avoidance of death are among the factors that can contribute to the use of futile treatments at the end of life.

Setting aside legal concerns and economic self-interest, what leads health care providers to prolong patients' suffering by futile attempts to beat the odds? What impels patients and families to request that "everything possible" be done when a loved one's death is clearly imminent? Finally, why do we as a society continue to expect medical miracles, rather than viewing death as an inevitable, natural part of life?

There is no single answer to these questions. Yet, the broader philosophical and historical context in which they arise may shed some light on why futile treatments are used and why acknowledging futility has been so difficult. One factor leading to the use of futile treatment is undoubtedly our contemporary conception of disease and corresponding attitudes toward death. Western medicine tends to view disease as an enemy to be fought, with death marking the ultimate defeat in this battle against disease. Such a conception has historical roots in the mid-19th century, when American medicine first began to identify itself effectively with a more aggressive scientific approach.[30] It was also during this time that the germ theory of disease became predominant, with its emphasis on isolating and destroying a foreign organism. In contrast to ancient Greek physicians who saw disease as an imbalance within the body, modern western physicians picture disease as a war waged against outside invaders.

Susan Sontag depicted modern medicine in these terms when she ascribed the controlling metaphor in the description of fatal diseases, such as cancer, as drawn from the language of warfare[31(p64)]:

[C]ancer cells do not simply multiply; they are "invasive" . . . "colonize" from the original tumor to far sites in the body, first setting up tiny outposts ("micrometastases"). . . . Rarely are the body's "defenses" vigorous enough to obliterate a tumor that has established its own blood supply and consists of billions of destructive cells. . . . the prospects are that "tumor invasion" will continue, or that rogue cells will eventually regroup and mount a new assault on the organism.

Likewise, the language of cancer treatment is infused with military images: in radiotherapy, "patients are 'bombarded' with toxic rays . . . chemotherapy is chemical warfare, using poisons"; all treatment aims to "kill cancer cells."[31(p65)]

A second factor that may contribute to a physiologic approach to end-of-life decisions is that the scientific method medicine employs tends to emphasize the physical signs of disease, while discounting the importance of patients' subjective experience of illness. According to some analyses, scientific medicine encourages a way of knowing in which people are seen as mechanical and deanimated. Thus, Hunter maintained that medicine "focuses on the measurable abnormalities of body and behavior that, by appearing regularly in cases of illness, are the indices of identifiable disease or injury."[32(p53)] Likewise, Keller argued that rather than encouraging empathic

understanding or a "feeling for the organism," scientific medicine emphasizes the empirical observation of physical facts.[33] Downplaying the importance of patients' experiences and subjective quality of life can lead to the mistaken equating of survival with success.

Third, the use of futile treatments at the end of life may reflect our own fear of death. In modern secular society, such fear may center on fear of the unknown, as well as the loss of the comfort afforded by previous religious understandings. As Callahan notes elsewhere in this issue, in contrast to the Puritans for whom death was a religious and family event, to put in God's hands, modern Americans tend to find little solace or meaning in death.[34]

Fourth, to the extent that the culture of medicine encourages actions over omissions and judges attempts to beat the odds as "heroic," the tendency will be to continue to use futile interventions. To the extent that practicing medicine is equated with using treatments, rather than with implementing a plan of care (which may include both actions and omissions), the tendency will be to regard withholding or withdrawing treatment as "doing nothing" or, worse, "abandoning the patient."[35]

Fifth, treatments may continue to be used beyond the point of benefit to patients merely as a result of not deciding what to do. One physician poignantly described his most frequent response when faced with decisions about using futile treatments for dying patients as avoidance[36(p719)]:

. . . not to make a conscious decision at all. . . . the problem is simply too difficult for me as a single human being to face in a conscious way. . . . On the other hand, how can I inflict the pain of aggressive treatment, and the suffering of further living, and spend the scarce resources of time and money on this person who is so obviously "trying" to die? And so, all too often, I don't make a conscious decision at all. I simply act, do something, make a decision without really considering the meaning of what I do.

Finally, whereas admitting medical futility requires acknowledging that medicine is sometimes powerless in the face of disease, continued efforts to beat the odds hold out the hope, however slim, of eventually mastering disease. As Nuland observed, fear of the loss and pain death portends can make it "more important to protect one another from the open admission of a painful truth [than to] achieve a final sharing that might have snatched an enduring comfort and even some dignity from the anguishing fact of death."[37(p244)] As a consequence, patients and families may keep up the charade of denial until the bitter end, clinging all the while to false hope, expecting to achieve a miraculous cure. Rather than exercising responsibility by educating patients and families about the hazards of excessive medical optimism, providers may instead prefer to put off such conversations indefinitely.

Conclusion

Those—dying then,
Knew where they went—
They went to God's Right Hand—
That Hand is amputated now
And God cannot be found—

The abdication of Belief
Makes the Behavior small—
Better an ignis fatuus
Than no illume at all
                    EMILY DICKINSON, 1845

Futile treatments can offer patients the illusion of continued life. They can offer families the false comfort of doing something. For health care providers, futile treatments may symbolize caring. Futile treatments thus perform vital functions; they are what Dickinson called an "ignis fatuus," something deluding or misleading that yet seems preferable to the absence of any understanding at all.

Despite their appeal, futile treatments should have no place in the humane care of dying patients. Although continuing to apply futile measures can offer a comfortable illusion, it is only by acknowledging, and moving beyond, futility that the dying process can become more dignified. Thus, when patients and families are no longer preoccupied with futile attempts to prolong life, they can turn their attention to preparing emotionally for death and to making practical decisions about the value of different settings for dying, such as the hospital, home, or hospice.[38] When health professionals are no longer preoccupied by futile technologies, they can focus instead on spending time with the patient and minimizing the patient's pain and discomfort. When those who surround the patient stop fighting for "everything" to be done, they can express love and concern in a more direct and meaningful way.[39] Only by redirecting our collective efforts in these ways will physicians help patients and make care of the dying a more honest and compassionate part of medical practice.

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